South Essex Branch

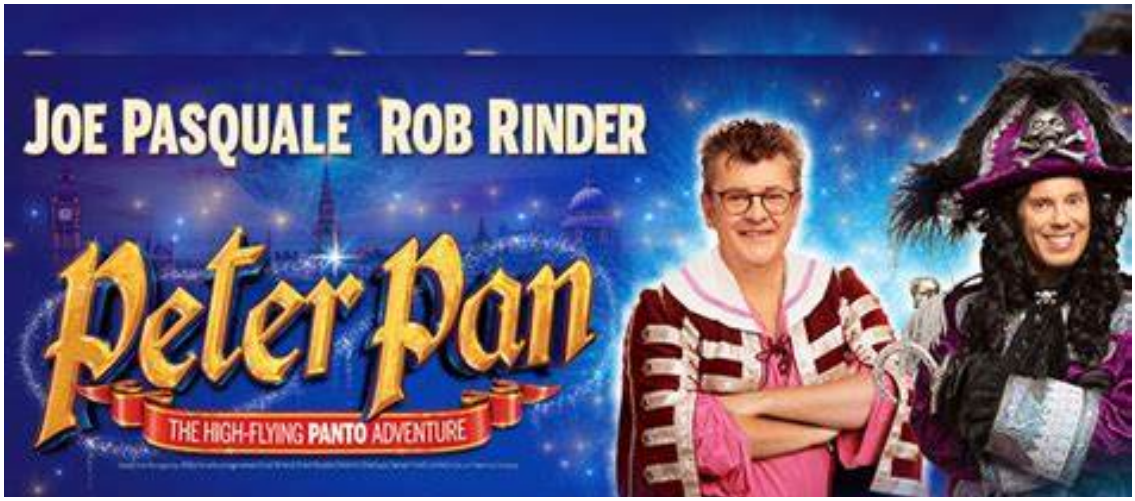
WINTER 24 NEWSLETTER

Registered Charity No. 294354

Branch President: Dr Stevan C. Wing Consultant Neurologist

www.mndsouthessex.org

Christmas Delights



It was wonderful to see so many of you enjoying our annual trip to the panto at Southend Cliffs Pavilion. Families and carers came too and shared the fun. This year it was Peter Pan with Judge Rinder as Captain Hook and Joe Pasquale as Mr Smee with a fantastic supporting cast. Loads of energy, loads of laughs, great scenery and spectacular costumes for the pantomime dame, Mrs Smee. We even discovered that Judge Rinder has a brilliant singing voice. We are really grateful to Rayleigh Lions for their generous support of £1150 towards the cost. The Cliffs Restaurant served us a tasty meal beforehand so there was plenty of time to socialize whilst eating and enjoying a drink.

Those who couldn't get to the panto received a gift of flowers, chocolates or a shopping voucher and Barry, Gill and Pat used this as a lovely opportunity to meet as many of you as possible when they did the deliveries.

Rowan Harvey from MND South Essex receiving the cheque from Alex Astley-Cooper, president of Rayleigh Lions, and fellow Lions Irene Pracy and Jeff Lagden.

RAYLEIGH LIONS DONATE £1150 FOR MND ASSOCIATION

by NEWS REPORTER

RAYLEIGH Lions have donated £1,150 to The Motor Neurone Disease Association South Essex (MND).

This will pay for 52 people living with MND and their carers and family members to see the pantomime at the Cliffs Pavilion this Christmas.

The pantomime is combined with their Christmas meal and will provide them all with some much needed festive entertainment and fun.

MND is a life-shortening disease and there is currently no cure. Although the disease will progress, symptoms can be managed to help achieve the best possible quality of life. The MND charity helps support those with the disease and their families.

this donation. We hope they enjoy the Christmas pantomime.

Since starting in 1974, Rayleigh Lions has raised and donated over £1 million to good causes in the Rayleigh, Hockley, Hullbridge and Rochford areas.

Big projects (approx £75,000) between 2015 & 2020 include:

- £15K towards new Hockley Day Centre mini bus
- £10K towards new prostate cancer treatment trial at Southend Hospital (joint project with other Lions clubs)
- £5K for Rayleigh Area at Farnham School paired pupils at Sweyne Park School
- £3K towards new scanner at Southend Hospital
- £5K for the mission of Essex Air Ambulance

Since Covid, with no fundraising for two years, Rayleigh Lions also donated around £10,000, including to Jack's sensory log cabin, Rayleigh REC Food bank, Rapid Response, Hospice for NHS workers), RNLI, East Essex Hospice, KAOS Youth Club, Essex Deaf Children Society, Westerings School, Zest Dog, Rochford Rayleigh Lions are always looking for members. If you are interested please rayleighlions.club@googlemail.com or

NEW EVENTS

Next AGM

Venue tbc (see Facebook page)
Saturday 16th March 11:30 till 15:00
Guest speaker and massages available.
Please let know Debbie if you can come.
rowananddebbie@btinternet.com

Restaurant Night

Great night out at Chinese restaurant **Zen City**, Hamlet Court Road, Southend on **Thursday 7th March**
3 course meal, £20 pp. Raffle prizes.
If you're interested, please contact Debbie
rowananddebbie@btinternet.com

Walk to d'feet

Our annual10 mile walk to raise money for our branch to benefit people living with MND in our area,
Sunday 12th May
will start at the seawall behind Leigh.
Please contact Michelle for info sheet and registration form.
mich.shabi@gmail.com

Easy Fundraiser

Downloading **Easyfundraising** app on your phone or tablet allows you to raise money for MND South Essex every time you shop big brands on line like for instance **Amazon, Booking.com, Boots, Ebay, Asos, all supermarkets...**etc.
You spend, brands donate!
Register on the app naming MND South Essex as your charity of choice and shop through Easy Fundraiser portal which will take you to your brand's online shopping platform.

MEET UP?

Meeting Dates

Drop in meetings 2-4pm
The hospices kindly let us use their lovely rooms for our get togethers. Chat and make friends. We will supply the food and drinks.
Fair Havens Hospice
St Luke's Hospice
Friday 2nd February - Fair Havens
Saturday 2nd March - St Luke's
Friday 5th April - Fair Havens
Saturday 4th May - St Luke's
Friday 7th June - Fair Havens
Saturday 6th July - St Luke's
Please contact Pat for more information
sessexmnd.pya@gmail.com

Recently Diagnosed Group

3rd Friday of the month via Zoom 2pm.
Allows all affected people to ask any question and find out about available support.
19th January/16th February/ 15th March / 19th April/ 17th May/ 21st June
Please contact Justine for details
justine.cox@mndassociation.org

South East Region Carers' Coffee and Chat

Evenings: Last Wednesday of the month via Zoom 6.30pm.
31st January/28th February/27th March/ 24th April/ 29th May/ 26th June
Daytime: 1st Tuesday of the month via Zoom 11am
6th February/5th March/ 2nd April/ 7th May/ 4th June
Please contact Justine for details
justine.cox@mndassociation.org

South East Region Peer Support Group

3rd Tuesday of the month via Zoom 11am.
16th January/20th February/ 19th March/ 16th April /21st May/18th June
Please contact Justine for details
justine.cox@mndassociation.org

Veteran's Group

3rd Friday of the month via Zoom 3-4pm.
19th January /16th February/15th March/ 19th April/17th May/21st June
Please contact Dawn Pond for details
dawn.pond@mndassociation.org

Research Update

A new possible precision-medicine gene therapy was shared at the 34th International Symposium on ALS/MND

Researchers from University College London and The Francis Crick Institute have developed a brand-new type of gene therapy that could be used to treat ALS, FTD and other neurodegenerative diseases. This new technique uses biology that is known to go wrong in neurons in MND and exploits it to increase the levels of proteins that are usually decreased in diseased motor neurons.

TDP-43 is a protein which becomes faulty in ALS and FTD and it's function of regulating protein instructions is lost. This means that the instructions can contain pieces of information that are not needed to produce the protein (cryptic exons). This new gene therapy relies on these cryptic exons being included. The therapy contains a gene that is engineered to have a cryptic exon which, when included in the protein instructions, kickstarts the cell to make a specific protein (such as UNC13a or Stathmin-2) which is usually reduced in the disease.

This precision medicine approach means that the gene therapy only acts in cells that are affected by the disease and only when TDP-43 becomes faulty. The gene therapy could help to reduce the toxic effects of faulty TDP-43 in neurons and restore protein levels in ALS/FTD.

Top-line results announced from phase 2b trial of potential treatment called Prime C

NeuroSense have announced the top-line results from the Phase 2b trial of Prime C. This Phase 2b trial included 69 people with ALS, from Canada, Italy and Israel, who were randomised to get either Prime C or a dummy drug (placebo) for six months. The initial results from this trial have shown that the potential treatment is safe and well tolerated by people with ALS. Prime C was also found to slow disease progression by 29% on the ALSFRS-R and slow decline in lung function by 13% for those on prime C compared to placebo.

While this was a small trial, the initial results are very promising and support the need for a bigger phase 3 trial, which is already being planned. Further results from this trial will be announced in early 2024 which will tell us more about how the treatment is working within the body.

Further results from the CNM-Au8 trial announced

Clene Nanoscience has reported additional data from the HEALEY ALS Platform trial. The additional data is from 'post-hoc' analysis of the trial, which means the analysis was completed after the trial was concluded and was not the primary objective of the trial.

Neurofilament light chain is a marker of nerve damage and levels are high in people with MND. Reducing the levels suggest a reduction in disease activity and less damage is happening to motor neurons. During the 24-week randomised portion of the trial, those who received CNM-Au8 had a 10% reduction in neurofilament compared to those who received the placebo. After 24-weeks, everyone on the trial was now able to receive the treatment. A 16% decrease in neurofilament from baseline to 76-weeks was found for those who received CNM-Au8 compared to those who initially received placebo.

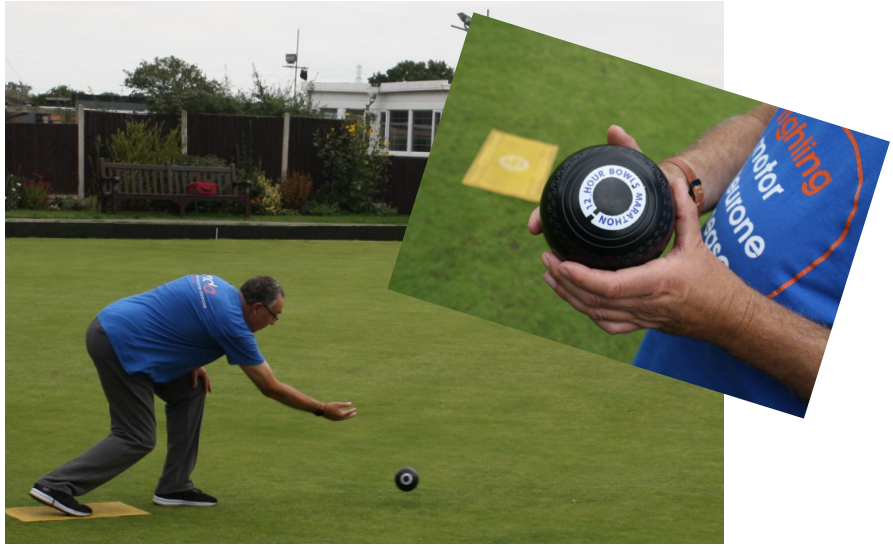
Clene also announced that they had approached the US Food and Drug Administration (FDA) to discuss accelerated approval for CNM-Au8. It has been reported that the FDA have rejected this request, stating that the results offered insufficient evidence of the reduction of neurofilament light chain

Raffle prizes

Please think of us for any unwanted Christmas gift as we are always grateful to get new raffle prizes.
Please contact Debbie
rowananddebbie@btinternet.com

12 hours Lawn Ball Challenge

Last October our very own **Barry** managed to finish 12 hours of lawn bowls in aid of MNDA.
As well as players donating to play against Barry, they also had a tombola, raffle, guess the number of sweets in a jar, and a raffle for a hamper and managed to raise an astonishing **£1,125** with more money still to come.
£250 has come from the Wickford branch of PROBUS.



The 7 in 7 in 7 Challenge and Extra Mile

On 7th December MND volunteers were asked to come and join Kevin Sinfield in Richmond Park for the last mile of his epic mega marathon, 7 marathons across 7 cities in 7 days and help him raise more money for the MNDA.

New JustGiving page

Please scan attached QR code to access the new JustGiving page for MNDA South Essex branch and use it for all your fund raising events.

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@MNDsessex

WHO'S WHO in your BRANCH

Stevan Wing: President
Philippe Udrzal: Chair/committee
Pat Ahlquist : Vice Chair/committee
Rowan Harvey : Treasurer/committee
Debbie Darke : Secretary/committee
Lisa Gallagher : fb/ committee
Marianne Morgan: committee
Kevin Watts : X/committee
Michelle Bingham : Walk to D'feet/committee
Gill Gibson : committee
Barry Mizen : web master/committee

Association Visitors

Pat Ahlquist : branch contact
Gill Gibson
Barry Mizen

Area Support Coordinator

Justine Cox